Reducing Stigma in Pregnant and Parenting Women with Substance Use Disorders
The MPATTC provides training and technical assistance on evidence-based practices in substance use disorder treatment and recovery services in Region 8 (North Dakota, South Dakota, Montana, Wyoming, Colorado, and Utah). We are funded by the Substance Abuse and Mental Health Services Administration (SAMHSA).
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Learning Objectives

• At the end of this presentation, participants will be able to:
  • Describe the unique differences in adverse stigma encounters experienced by women who are pregnant and parenting
  • Recognize the consequences of stigma related to substance use disorders in women who are pregnant and parenting
  • Consider opportunities to reduce healthcare stigma experienced by women with substance use disorders who are pregnant and parenting
Substance Use Disorder (SUD) Defined

“Chronic, relapsing disorder characterized by compulsive drug seeking, continued use despite harmful consequences, and long-lasting changes in the brain. It is considered both a complex brain disorder and a mental illness.”

“Addiction is the most severe form of a full spectrum of substance use disorders, and is a medical illness caused by repeated misuse of a substance or substances.” (NIDA, 2018)
2019 National Survey on Drug Use and Health: Women (SAMHSA, 2020)

Mental Illness and Substance Use Disorders in America among Women (≥18 y.o.)

Among women with a substance use disorder:
- 2 IN 5 (40.8% or 2.9M) struggled with illicit drugs
- 3 IN 4 (72.5% or 5.2M) struggled with alcohol use
- 1 IN 8 (13.3% or 956K) struggled with illicit drugs and alcohol

Among women with a mental illness:
- 1 IN 4 (26.6% or 8.4M) had a serious mental illness

5.6% (7.2 MILLION)
People aged 18 or older had a substance use disorder (SUD)

3.6% (4.6 MILLION)
People 18 or older had BOTH an SUD and a mental illness

24.5% (31.7 MILLION)
People aged 18 or older had a mental illness

In 2019, 34.3M adult women had a mental illness and/or substance use disorder—an increase of 6.8% over 2018 composed entirely of increases in mental illness.
Alcohol Use Among Women

Alcohol Use among Women

Alcohol Use Disorder among Women

(NSDUH, 2020)
Illicit Drug Use Among Women

- Women are at highest risk for developing SUDs during reproductive years
- Polysubstance use is common
- Unintended pregnancy rate among women with SUD is ~80%
- Substance use in pregnancy connected to many complications / negative health outcomes for mom/baby dyad

Data from NSDUH, 2020
Past Month Substance Use Among Pregnant Women

Past Month Substance Use among Pregnant Women

Illicit Drugs
- 2016: 143K, 6.3%
- 2017: 194K, 8.5%
- 2018: 128K, 5.4%
- 2019: 120K, 5.8%

Tobacco Products
- 2016: 239K, 10.6%
- 2017: 334K, 14.7%
- 2018: 271K, 11.6%
- 2019: 198K, 9.6%

Alcohol
- 2016: 187K, 8.3%
- 2017: 11.5K, 8.3%
- 2018: 261K, 9.9%
- 2019: 233K, 9.5%

Marijuana
- 2016: 111K, 4.9%
- 2017: 161K, 7.1%
- 2018: 111K, 5.4%
- 2019: 112K, 5.4%

Opioids
- 2016: 26K, 1.2%
- 2017: 32K, 1.4%
- 2018: 22K, 0.9%
- 2019: 8K, 0.4%

Cocaine
- 2016: 2K, 0.1%
- 2017: 8K, 0.4%
- 2018: 8K, 0.4%
- 2019: 3K, 0.2%

* Estimate not shown due to low precision.

Tobacco products are defined as cigarettes, smokeless tobacco, cigars, and pipe tobacco.

+ Difference between this estimate and the 2019 estimate is statistically significant at the .05 level.
Stigma Defined

Stigma associated with substance use disorders is a significant barrier to detection and treatment efforts. Women are particularly impacted. Women experience unique differences from male counterparts that may lead to increased stigma.
Different Views of Stigma

• Perceived stigma
  • Internalized negative belief that others have a commonly held stereotype about a stigmatized group

• Public stigma
  • Endorsement of stereotypes by general population through discrimination
    • Found in communities, including private and governmental organizations that intentionally or unintentionally proliferate stigma
    • Can undermine delivery of lifesaving programs and interventions (Recto et al., 2020)
Different Views of Stigma

• Self-stigma
  • Internalized negative belief that someone holds about themselves
  • 4 stages:

<table>
<thead>
<tr>
<th>Becoming aware of stigmatization</th>
<th>“Society thinks I am a bad person”</th>
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<tbody>
<tr>
<td>Agreeing with stereotypes and prejudice</td>
<td>“They’re right, I am a bad person”</td>
</tr>
<tr>
<td>Self-application</td>
<td>“I have this condition; therefore, I am a bad person”</td>
</tr>
<tr>
<td>Decrease in self-esteem and self-efficacy</td>
<td>“Why should I even try”</td>
</tr>
</tbody>
</table>

• Overall impact of stigma may indirectly sabotage treatment outcomes by sustaining negative emotions
  • Psychological stress especially common during perinatal period

(Recto et al, 2020)
Differences in Stigma for Women with SUD

• Women face unique and distinct differences in stigma from male counterparts
  • The Impact of Biology
    • Women experience Telescoping
      • A faster onset and progression of SUDs than males
    • Women more susceptible to cravings and return to use
    • Menstrual cycle may play a role in response to substances
    • Women metabolize alcohol and drugs differently
      • Fewer stomach enzymes and more fatty tissue slow down processing which contributes to higher concentrations of substances longer
Stigma IS Different for Women with SUDs

• **Cultural Impact**
  • Greater stigma as a result of traditional societal roles
    • Gatekeepers
    • Mothers
    • Caregivers
    • “Central organizing factor in family units”
  • Prolonged isolation may be more common among stay-at-home moms
  • Greater impairments in social functioning, such as relationships and employment
    • i.e. Start/Stop career options
Stigma IS Different for Women with SUD

• **Gender Specific Sensitivities**
  - SUDs in women have historically been considered selfish, a moral failure
    - Believed to result in intentional harm to family, child, and placing burden on society
    - Strongly drives “self-stigma”
      - Internalization of a narrative of blame, shame and guilt
      - Struggle between “secrecy and disclosure”

• **Economic barriers to treatment**
  - Less income, pay gaps, higher likelihood of living in poverty prior to SUD onset

• Stigma disproportionately noted among poor women and women of color (Chou et al., 2018)

• Higher % of women have history of trauma (Research Recovery Institute, n.d.; National Academy for State Health Policy, 2018)
Stigma IS Different for Women with SUD

• Women are more prone to co-occurring disorders
  • In 2019, 34.3M adult women had a mental illness and/or SUD \textit{(NSDUH, 2020)}
    • Increased risk for suicidality among women
    • ~30% or pregnant women enrolled in SUD treatment screen positive for depression; ~40% report postpartum depression
    • Stigma noted for each concern
  • Among women, use of one substance—alcohol or other illicit substance-- is strongly correlated with polysubstance use, major depressive episode, serious mental illness
    • Despite these facts, providers tend to miss signs of addiction and mental health concerns, especially in older women and younger females
    • Need to screen for all substances as well as mental health issues, \textit{and} treat all co-occurring disorders
Stigma IS Different for Women with SUD

• **Motherhood**
  - Pregnant women with SUDs increasingly stigmatized/prosecuted for substance use, leading to financial, emotional, and legal consequences in this population
  - Postpartum (first year and beyond), mothers with SUD continue to perceive stigma from
    - Healthcare providers
    - General public
    - Loved ones
    - Themselves
    - Addiction community (Frazer, McConnell, Janssen, 2019; Paterno, Low, Gubrium, Sanger, 2019)
  - As many as 70% of women entering addiction treatment have children AND primary responsibility for children
    - Family responsibilities can interfere with regular attendance in treatment sessions
    - May be more hesitant to seek treatment for fear of legal action and social service involvement
Stigma IS Different for Women with SUD

- Preconception Planning:
  - Chronic Medical Conditions
    - Hypertension
    - Diabetes
  - Perinatal Depression
  - SUD/OUD

- Other Thoughts for Self-Reflection:
  - Response to filling a prenatal vitamin along with MOUD
  - Breastfeeding planning with SUDs
  - Discussing alcohol use while trying to conceive
  - Stopping contraception to conceive when active SUD present or in treatment
Understanding Culture, Health Care, & Stigma

• Each health care interaction occurs in context of three cultures
  • Healthcare provider’s lived experiences
  • Experiences of person seeking care
  • Culture of healthcare system itself

• Wide variations in attitudes, beliefs, behaviors, exist among all individuals
  • This includes bias and stigma

• “A single interaction with a healthcare professional can be empowering…or one that negatively impacts all subsequent interactions…” (Locke, 2020)
Discussion Point

• Share Experiences about a “Not so pleasant” Healthcare Encounter (either provider or consumer)
  • Did the experience impact your future care options?
  • Can you recognize stigmatizing behaviors now that occurred at the time of the encounter?
  • Have you thought about the encounter since it happened?
So Consider This…

If a mother seeks treatment for SUD or discloses her SUD during her pregnancy, she may, at a minimum, have the following perinatal interactions

- Prenatal visits: 9
- Labor and delivery stay: 2 days
- Postpartum visit: 1

AND

- Remember, each interaction occurs in a context of three cultures

THEREFORE

- She potentially faces at least 36 negative stigmatizing experiences from routine perinatal care ALONE!

AND

- This doesn’t include interactions with family, friends, colleagues, the addiction community, behavioral health professionals AND the subsequent encounters that she may occur over the first year postpartum, i.e. newborn/pediatric appointments, WIC visits, family planning visits
Five Types of Adverse Encounters

• Mothers with SUD may experience the following encounters (Renbarger, Shieh, Moorman, Latham-Mintus, & Draucker, 2019)
  • Judgmental
    • Sense providers’ disapproval of SUD
    • “Look down on them”
    • Sense blame when infants experience withdrawal symptoms
    • Feelings of shame, frustration, irritation and being dismissed during visits
  • Scrutinizing
    • Feel closely observed or monitored
    • Identified as “Drug User”
    • Causes mothers to avoid prenatal care, lie about SUD, use other women’s urine for drug testing
    • Feel watched for indications they were “high” when holding infants, visiting NICU, breastfeeding
    • Feel questioned about ability to mother
      • Inhibits mother-infant bonding
Five Types of Adverse Encounters

• **Disparaging**
  - Overt critical behaviors
  - Experience eye-rolling, name calling “Addict,” “Junkie Mom,” “Methadone Mom” told to “Get their life together”
  - Whispering
  - Results in sense of low self-worth

• **Disempowering**
  - Cause mothers to feel like they have little or no control over own health and infant’s health
  - Don’t feel believed, listened to or feel like health concerns taken seriously
  - “No voice” in healthcare decisions, type of SUD treatment
  - Feelings of frustration and anger
Five Types of Adverse Encounters

• **Deficient care**
  - Mothers often feel they receive lower quality of care because of substance use
  - Feel they are not provided with adequate health information
  - Lack of time during visits secondary to SUD
  - Causes mothers to discontinue care
  - Mothers desire **MORE** information about SUD in pregnancy, SUD treatment options and breastfeeding
Other Forms of Stigma

• **Mislabeling**
  • “Crack babies” and “Junkie mom”

• **Misinformation**
  • “Babies are born addicted”
    • Infants may experience withdrawal symptoms maternal substance use and abuse, BUT they are not born addicted.
    • American Society of Addiction Medicine describes addiction as a “treatable, chronic medical disease involving complex interaction among brain circuits, genetics, the environment, and an individual’s life experiences. People with addiction use substances or engage in behaviors that become compulsive and often continue despite harmful consequences.” (ASAM, 2019)
      • Does an infant really have these experiences?
  • “MOUD should not be used during pregnancy/ breastfeeding”
    • Our best evidence reports safety of use in the perinatal period

MOUD: Mediations to Treat Opioid Use Disorder
Other Forms of Stigma

• **Media** (Avery & Avery, 2019)
  • Most Americans get health information from news media, social media, public information campaigns

• **Agenda setting**
  • Topics receiving high levels of media attention likely perceived by public as priorities for intervention
  • Focuses attention on topics likely to generate/mitigate stigma toward a population
    • Illicit drug use typically receives more media than alcohol/tobacco
    • Stigmatizing attitudes greater toward people who use illicit drugs

• **Framing**
  • Emphasizes certain aspects of an issue over others; influences how public views that issue
    • Consequence framing: Emphasizes consequence of problem of interest over others
      • FAS/FASD campaigns: Highlight consequences of alcohol use on fetus; rarely mentions maternal impact or treatment
      • Drug epidemic: Children left without parents
Other Forms of Stigma…YES!

- **Devaluing maternal relationship with child**
  - “Saving” the vulnerable infant from the “harming mother”; restricting participation in initial infant care (Frazer, McConnell, & Janssen, 2019)

- **Punishment**
  - Forced detoxification from treatment with MOUD
    - Women are already more likely to discontinue MOUD during postpartum period than pregnancy
  - Incarceration during pregnancy
    - Guttmacher Institute: Substance Use During Pregnancy:
      - 23 states and District of Columbia consider substance use in pregnancy child abuse
        - 3 as grounds for civil commitment
      - 25 states require health care professionals to report suspected prenatal drug use
        - 8 require them to test for prenatal drug exposure if suspect drug use (as of 2-1-21)

*NO evidence that criminalization functions as a deterrent!*

*American College of Obstetricians and Gynecologists (2015; 2017) calls for efforts to improve availability of treatment and rehabilitation services and to ensure that pregnant women with SUDs who are seeking prenatal care are not criminalized*
<table>
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<tr>
<th>STATE</th>
<th>SUBSTANCE USE DURING PREGNANCY CONSIDERED:</th>
<th>WHEN DRUG USE DIAGNOSED OR SUSPECTED, STATE REQUIRES:</th>
<th>DRUG TREATMENT FOR PREGNANT WOMEN</th>
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<td>Child Abuse</td>
<td>Reporting</td>
<td>Perinatal Substance Use</td>
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<td>Grounds for Civil Commitment</td>
<td>Testing</td>
<td>Treatment for Pregnant Women</td>
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Information for WY Not Available

Global Comparisons to U.S. Health Care

• Australia
  • Each state and territory have requirements about reporting the potential for harms from substance use to the unborn child
  • Guidelines recommend that pregnant women with SUDs benefit from appropriate referral for specialist drug and alcohol assessment
  • Over-arching emphasis is placed on importance of establishing an effective, trusting relationship with the woman with SUD during pregnancy
    • Encourage a holistic approach based on respect and a non-judgmental attitude that engages “the woman into adequate antenatal care and maintains continuity of care and carers throughout the pregnancy and postnatal period” (Australian Government Department of Health, 2018, p. 98-100)
Global Comparisons to U.S. Health Care

• No global guidelines provide recommendations for identifying and managing substance use and SUDs in pregnancy

• Several high-income countries have developed national guidelines, but low- and middle-income countries lack similar guidance (WHO, 2014, p. x)

• **Canada**: “There are no laws specific to substance use during pregnancy” and “health care providers do not have a legal obligation to make a report about prenatal substance use” (Canada FASD Research Network, 2014, p. 3-5)
  - The Society of Obstetricians and Gynaecologists of Canada (2017) acknowledges the unique and complex needs of women with SUDs
  - Canadian health care providers are encouraged to employ a flexible approach to women with SUDs in the perinatal period through a harm reduction philosophy of care
Access Barriers to SUD Treatment During Pregnancy and Postpartum

• The single act of accessing treatment, identifies
  • The woman as having a SUD AND
  • Her infants and children who are substance-exposed

• In addition to stigma, other barriers include:
  • Lack of access to gender-specific care
  • Limited child-care availability at treatment facilities
    • Not wanting to leave children or a partner at home
    • Minimal access to transportation or childcare, limited availability on housing units
      • *Attendance and retention best predictors of treatment success
  • Few providers with obstetric AND addiction treatment expertise, especially in rural areas
  • Fear of criminal or child welfare consequences
  • Perinatal period is actually a very short period of time to receive services
    • Wait times to access may be prohibitive
Consequences of Stigma, Perceptions, Biases

- Poor self-image / Poor self-esteem
- Shame / Embarrassment
- Fear
- Depression / anxiety
- Defensiveness
- Suboptimal prenatal care
  - Direct impact on fetus AND mother
    - Impacts growth, missed warning signs for OB complications, lack of emotional support
    - Increased risk of NOT breastfeeding
    - Care NOT grounded in empathy and respect can retraumatize women, trigger return to use and further impede access to care (Kramlich et al., 2020)
- NOT engaging in MOUD during pregnancy or breastfeeding or withdrawing early from treatment
- Incarceration
- Death (Frazer, McConnell, & Janssen, 2019)
Healthcare Providers & Stigma

• Do Healthcare Providers Experience Consequences of Stigma Too?
  • Do we feel stigmatized because we care for childbearing women with OUD?
    • i.e. providers who prescribe Medications for OUD are often told “You are just replacing one drug with another”
    • i.e. “You’re giving ‘them’ (mothers in labor) MORE pain medication?”
  • Do our experiences with seeing how women with SUD/OUD are stigmatized prevent healthcare providers with SUDs from reaching out for the same care?
    • Addiction occurs among healthcare professionals at rates similar to general population
    • Complexities of disclosure: loss of license, employment, restrictions upon return to work, guilt, shame
    • Nurses Study: Upon disclosure of an SUD, nurses reported hearing: “personal choice, a failure of moral character” rather than colleagues seeing their SUD as a disease
      • Does this sound familiar to stigma faced by women who are pregnant/parenting with SUD?
  • Do we feel bias toward our peers with SUD?
“The way a mother experiencing Perinatal Substance Use Disorder is treated, and her view of herself as being a capable (or incapable) mom, will impact how her relationship and attachment with her baby develops.” (MAIMH, 2017)

We have work to do!
How Can We Improve Care?

• Everybody’s Language Matters
  • View addiction as a chronic disease, not a moral shortcoming
  • Use nonbiased language in health care encounters

• Education
  • Present and discuss the facts
  • Correct MIS-information
  • Increase training for health care professionals (Merrill & Monti, 2015)
  • Increase community awareness

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<tr>
<th>Words to Avoid</th>
<th>Words to Try</th>
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<tbody>
<tr>
<td>Clean</td>
<td>In Recovery</td>
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<tr>
<td>Dirty Test</td>
<td>Positive drug test</td>
</tr>
<tr>
<td>Relapse</td>
<td>Recurrence of use</td>
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<tr>
<td>Addict, Junkie</td>
<td>Woman with substance use disorder</td>
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<tr>
<td>Drugs</td>
<td>Medications</td>
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<tr>
<td>Substitution therapy</td>
<td>Treatment for opioid use disorder</td>
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</table>
How Can We Improve Care?

• **Improve interprofessional communication**
  • Perinatal health care providers may not be well-informed about addiction and substance use treatment
  • Recovery professionals may not be sensitive to women’s unique needs during pregnancy and postpartum

• **Encourage increased clarity**
  • Clear medical history, trauma history, medical needs, & social service needs can lead to more holistic care

• **Implement well-coordinated, integrated care**
  • Integrated care includes services for pregnancy, parenting, or children in combination with substance use treatment in one setting (Tarasoff et al. 2018)
  • **Remember the Impact of Co-Occurring Disorders**
    • Treat co-morbid behavioral health disorders before, during, post-pregnancy
      • Quality treatment options MUST consider quality of life for mother too
How Can We Improve Care?

• **Pregnancy** may provide a “WINDOW of OPPORTUNITY” to engage in treatment and recovery (ACOG, 2017; Terplan, McNamara, Chisolm, 2012; Terplan & Minkoff, 2017)
  • Be open and transparent about testing and reporting requirements
  • Universal screening (self-report)
    • Drug testing done with consent of the pregnant woman; understand right to refuse testing
    • Consider standardized screening for substance use through self-report
  • Consider peer services, group prenatal care programs
    • Peer support can be a counterbalance to discrimination, rejection, isolation that may sustain longer term and more regular treatment utilization
How Can We Improve Care?

• Gender-Attentive care options
  • Most treatment and recovery for women has been programmed around pregnancy
    • Also need to address gender specific needs outside of pregnancy
      • Trauma history
        • Intimate Partner Violence
        • Sexual trauma
        • Victimization
      • Housing support
      • Social services needs
      • Income support
      • Employment
How Can We Improve Care?

• Sexual Reproductive Health Services: Contraception
  • Women spend an estimated 5 years of life trying to conceive, pregnant, immediately postpartum, BUT 30 years trying not to get pregnant!
  • Include family planning in treatment and recovery
    • Healthcare professionals have privilege: this can influence how we “package” our information about contraception to women with SUDs (Locke, 2020)
      • Offer respectful discussions that include choice preferences
  • Women with SUDs have been targeted for forced and coerced sterilization (Charron et al., 2020); often experience discrimination around reproductive health choices
  • Stigma related to substance use is one of the most significant barriers to accessing sexual reproductive health services noted by both providers and patients (MacAfee et al., 2019)
  • SUD treatment is a critical time to offer SRH services, including STI screening and contraception as many women have not had access to these services prior to treatment and many may lose contact with providers following treatment

• Empower Women to be Partners in Their Healthcare
Affect Change

- **Advocate for Legislative and Policy Change**
  - Punitive laws/actions against pregnant women can serve as barriers to trusting patient-provider relationship
    - 19 states have created/funded drug treatment programs specifically targeted to pregnant women
    - 17 states and District of Columbia provide pregnant women with priority access to state-funded drug treatment programs.
    - 10 states prohibit publicly funded drug treatment programs from discriminating against pregnant women (Guttmacher, 2021)
  - Many women lose public health insurance coverage during postpartum period
    - Discussions ongoing to extend coverage through first year postpartum
Affect Change

• Promote Health
  • The World Health Organization has defined health as not merely the absence of disease, but the presence of optimal social, psychologic, and physical well-being
  • “Prevention and treatment interventions should be provided to pregnant and breastfeeding women in a way that will prevent stigmatization, discrimination and marginalization, and promote family, community and social support, as well as social inclusion”
Affect Change

• Promote Reproductive Health
  • Reproductive Health comes with Reproductive Rights
    • The right of all individuals and couples to
      • Information
      • Education
      • Choice about number and timing of one’s births
      • Attainment of the highest level of reproductive health
Affect Change

• **Support Providers**
  - Caring for families impacted by SUDs can be connected to ethical distress, moral distress, and compassion fatigue
    - It can be helpful for all us to:
      - Become more aware of our own biases
      - Continue to increase personal knowledge about mental health and SUDS
      - Learn more about intimate partner violence and family dynamics in the context of SUDs
      - Become aware of local and state treatment options for pregnant and parenting women with SUDs (Recto et al, 2020)
    - Engage in Self-Care
    - Be kind….to each other
The ACTS Script

- **ACTS** is a guide for responding respectfully and constructively to clinical situations where you see your coworkers stigmatizing or judging your patients

- **Acknowledge**
  - Create an opportunity to open the dialogue
  - Do not criticize

- **Create Circumstance for Reflection**
  - Ask questions or think out loud

- **Teach**
  - Share an article
  - Ask permission to share some knowledge about what you have learned

- **Support**
  - Encourage peers to try new approaches to clients and then debrief those approaches
  - Celebrate successes!

- Please consider “ACTing” when you encounter a colleague who is using stigmatizing language

Yes, the Stigma is Real…
But so is the Opportunity to Impart Change
and
Support Pregnant and Parenting Women with SUDs
THANK YOU!
• Worth the Watch
  • YouTube: Dr. Mishka Terplan, MD, MPH -- “Gender & Use, Misuse, Treatment and Recovery” (May 17, 2017)

  Dr. Mishka Terplan talks about how developing addiction to opioids and other drugs vary across gender, and how those expectations impact the conception of treatment and stigma around use. Dr. Terplan is a Professor of Obstetrics and Gynecology and Psychiatry and the Associate Director of Addiction Medicine at Virginia Commonwealth University. The From Research to Recovery Town Hall brings together speakers from across the country to address mental health, substance use and other facets of behavioral and emotional health.

https://www.youtube.com/watch?v=siC6Cd4Q3MQ&t=33s
References


• Substance Abuse and Mental Health Services Administration. (2009). Treatment improvement protocol (TIP) series, No. 51. Chapter 7: Substance abuse treatment for women. Addressing the specific needs of women

